

# Dystonia Canada Report

DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION  
CANADA



FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

*serving all dystonia-affected persons  
déservant toutes personnes atteintes de dystonie*

A Newsletter from Dystonia Medical  
Research Foundation Canada

Spring/Summer  
2026

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2026 Freedom to Move Ambassador, Laurence Guénette-Rochon, alongside her mother, Pascale



**50 Years of Impact:  
Built by Our Community,  
For Our Community**



Members of the Montreal Support Group, Dystonie-partage, 2018



DMRF Canada Support Group Leaders gather at 2018 Calgary Symposium



Toronto Support Group Members take on the Toronto Waterfront 5K Challenge 2025



Freedom to Move: Run, Walk and Wheel for Dystonia 2024



Greater Sudbury and District Support Group's Freedom to Move Walk 2016

## PLEASE RENEW YOUR MEMBERSHIP FOR 2026

Support the dystonia community with a donation to DMRF Canada.

visit: [www.dystoniacanada.org/donate](http://www.dystoniacanada.org/donate)

Thank you for your support.

# Foundation Update

Dear Friends,

Founded in 1976, by Samuel and Frances Belzberg, this year marks 50 years for DMRF Canada. This means, for 50 years we have been working towards our mission.

This mission includes promoting awareness and education as well as supporting the needs of individuals and families affected by dystonia. While these remain important, at the heart of our organization has always been advancing research for better treatment and ultimately a cure for dystonia. We have seen progress in treatments and some people living with dystonia are thriving, but we cannot “celebrate” 50 years because do not have a cure.

**What we can recognize is 50 years of building a community with a common goal. Every educational event, support group meeting, fundraiser, research grant and connection made possible by our volunteers strengthens our community. Each time someone gets an earlier diagnosis, access to more effective treatments or simply knows they are not alone in their experiences, we see the positive impact of this community.**

Throughout this report, we highlight many of the achievements of the dystonia community. We invite you to read them with an open mind and ask yourself how you or those in your network can continue to bolster this community, so we make further strides towards our mission.

We are pleased that the year has already been off to a great start with more hands on deck to support us. We welcome Catherine Mulkins, now serving as co-chair as well as new board members Joe Murphy and Eli Konorti.

We thank each one of you who give generously with your time, experience and financial support. We couldn't do it without you.

Sincerely,



Connie Zalmanowitz,  
Co- Chair, DMRF  
Canada, Board of  
Directors

*Connie Zalmanowitz*



Catherine Mulkins,  
Co- Chair, DMRF  
Canada, Board of  
Directors

*Catherine Mulkins*



Archana Castelino,  
National Director,  
DMRF Canada

*Archana Castelino*

## Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRF Canada funds medical research toward a cure, promotes awareness and education, and supports the well-being of affected individuals and families. We work in partnership with the DMRF in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and with other like-minded research organizations to fund excellent dystonia research in Canada.

### Board of Directors

Samuel Belzberg  
Co-Founder  
1928 - 2018

Frances Belzberg  
Co-Founder &  
Honorary Chair

Connie Zalmanowitz  
& Catherine Mulkins  
Co-Chairs

Pearl E. Schusheim  
Secretary/Treasurer

### Directors

Lance Howitt  
Dennis Kessler  
Casey Kidson  
Eli Konorti  
Rosalie Lewis  
Joe Murphy

## You Can Help Shape Dystonia Research -Sign Up Today!

The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia. Although the focal dystonias have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different patient populations may help us identify the common features that they may share.



Visit: [www.globaldystoniaregistry.org](http://www.globaldystoniaregistry.org) to learn more and register

## In Tribute

DMRF Canada extends our condolences and gratefully acknowledges the generous gifts received in memory of the following:

Ralph Gibson

Paul Kennedy

Evelyn Pistun

Renee Hamilton

Sara Rita Lawrence

Brenda White



## Dystonia Journal Update

The DMRF's official journal, aptly titled Dystonia has now published over 70 articles and provides open access premier research on all basic, clinical, and translational aspects of the different forms of dystonia.



To stay up to date on the latest development, please visit [www.frontierspartnerships.org/journals/dystonia](http://www.frontierspartnerships.org/journals/dystonia)

## Dystonia Symposia This Fall

Our Greater Toronto Support Group and our French-speaking Montreal Support Group, Dystonie-partage, will host special dystonia events in their respective cities in honour of the Foundation's 50th anniversary. **Stay tuned for more details in the coming months.**

# Welcoming Catherine Mulkins as New Co-Chair

You may have noticed a new name in our recent foundation update. Catherine Mulkins has joined Connie Zalmanowitz as Co-Chair of DMRF Canada. Like many on our Board, Catherine's involvement is rooted in a personal connection to dystonia. But she also brings a perspective new to this role, as the first board chair living with dystonia.

Catherine started experiencing symptoms of dystonia before the age of 10. She recalls never being good at games that required a steady hand, like the family favourite Operation. She endured years of symptoms, most notably a tremor, requiring resourcefulness and modifications throughout her life. Her tremor has been progressive, making writing increasingly challenging. She eventually had to train herself to write with her non-dominant hand and now is unable to write. "Getting through university was a challenge," she remembers. "Everything was handwritten. I didn't get extra time for exams or assignments. They weren't big on accommodations back then."

Even if accommodations were available, Catherine didn't have a diagnosis until she was referred to a movement disorders clinic at 41 years old. Following her dystonia diagnosis, Catherine remembers feeling a mix of emotions. There was validation that her symptoms could be explained by something as well as fear that in her case, dystonia was progressive and hereditary.



Sisters Christine, Catherine and Jenny Mulkins, in the early days of their involvement with DMRF Canada and formerly Chuck's Run, now Freedom to Move: Run, Walk and Wheel for Dystonia.

To support Catherine following her diagnosis, her sister Jenny discovered DMRF Canada and offered to volunteer with their major fundraising event, formerly Chuck's Run, now Freedom to Move Run Walk and Wheel. "That's what first got me involved in the foundation," she explains.

Eventually, Catherine's son was diagnosed with dystonia, as well as Jenny's son and her other sister, Christine's daughter. Catherine's family had been a strong support system all her life. Now there was a diagnosis and there was the next generation of family members with dystonia to consider. They wanted to take action and became active volunteers within the community. Each year they rally friends and neighbours for the annual Freedom to Move fundraiser, consistently ranking as one of the top fundraising teams.

*Article continues on page 5*



Catherine at the 2025 Freedom to Move for Dystonia event in Toronto.

"I have been blessed in life to be surrounded by so many supportive family members, friends, coworkers and neighbours."

- Catherine

Fundraising has been at the heart of Catherine's volunteer work. While this remains a focus, she is also bringing a skillset from her career in human resources. In 2022, Catherine retired after 21 years at Intact Insurance. During her time at Intact, and following her diagnosis, she found a new support system in her leaders and colleagues, including workplace accommodations. "I really can't say enough good things about the organization, the people and their values," Catherine emphasizes. "With Freedom to Move, in addition to family and friends, my coworkers began to participate in the walk. They would donate to my team and Intact would match contributions from anybody on my team that worked at Intact."

Catherine is grateful to have such caring and loyal support from her family, friends, neighbours and co-workers. "I found it hard to ask for help but eventually I realized I was surrounded by wonderful people who want to help however they can." Catherine describes the support she receives as her lifeline. She lights up, especially when talking about the close relationship she shares with her family. "They fill out my forms, sign my name, and hold my glass at a party. Dystonia can make me dangerous in the kitchen and my husband cooks and cleans up broken pieces like it's no issue at all."

Catherine does not take her support network for granted and it inspires her to give back. She hopes she can serve as a positive example for others. "I want to model for other people with dystonia that they can give back to the community and share their own stories," says Catherine. She cites a recent example where through her board work, she met a woman who had been recently diagnosed with dystonia. She had experienced trauma surrounding the diagnosis and was feeling alone. "Sometimes when you first get diagnosed, you want to be able to give back and do something, so you don't feel so

helpless," she empathizes. Catherine was able to connect her with the Freedom to Move virtual events. She created her own team to take part, giving her a sense of agency in stressful circumstances.

Catherine's career also gives her a helpful lens to view the future of the board. "Succession planning was part of my work in HR," Catherine says. Recognizing that many board members may be close to retiring, Catherine hopes she can bring her expertise to set DMRF Canada up for a successful future. "We've been fortunate. The current board members are dedicated, bright, committed, and they've given a lot."

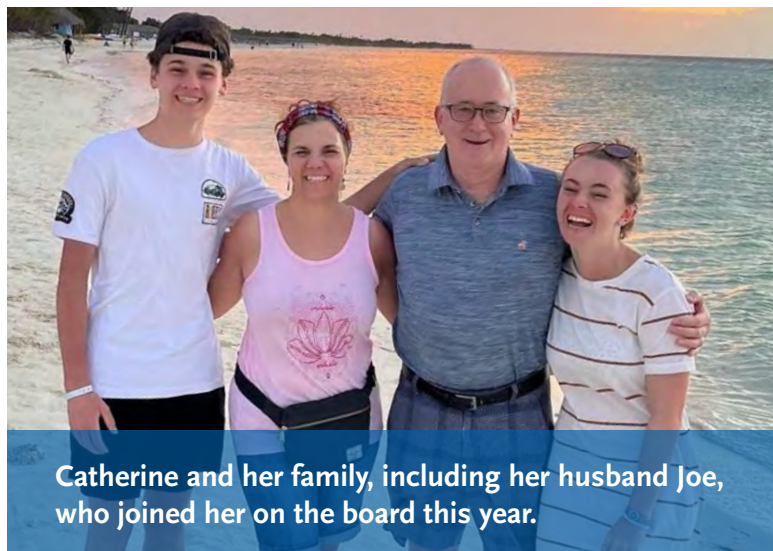
She has immediately become engaged in finding volunteers to fill some positions. When Catherine heard the board was searching for someone with financial acumen, she didn't have to look further than her own home, recruiting her husband, Joe Murphy to apply. "He has an interest in finances. He's taken the Canadian Securities course, and a wealth management course. He follows the stock market out of interest."

After a successful application and interview process, Joe will be joining the board, continuing the trend of making dystonia volunteerism a family affair.

Catherine recognizes experience as Co-Chair will also give back to her. "My career, as much as I loved it, was intense. I was with a high performing organization which requires a lot of work and takes a lot out of you

mentally." She feels her work with DMRF Canada will provide the opportunity to keep her mentally challenged. "I like having the board work so I still have something that will keep me learning and engaged in something that is meaningful for me."

DMRF Canada is happy to welcome Catherine Mulkins as Co-Chair of the Board. Her skills and talents will be a wonderful addition to our current work and the future of dystonia fundraising, research and advocacy, working towards a cure.



Catherine and her family, including her husband Joe, who joined her on the board this year.



# Freedom to Move: Run, Walk, and Wheel for Dystonia Returns in June!



We are thrilled to announce the return of our signature event, **Freedom to Move: Run, Walk, and Wheel for Dystonia**. Each June, Canadians from across the country unite to raise awareness and vital funds for the dystonia community. Thanks to the incredible support of our participants and donors, this event has raised more than \$1 million to advance research, advocacy, and essential programs for people living with dystonia.

**Join the movement! Gather your supporters to walk, run, or wheel virtually in your own neighborhood, or meet us in person at Toronto's Downsview Park on Sunday, June 14, 2026.**

For the third consecutive year, we are proud to partner with fellow neurological health charity Hydrocephalus Canada to co-host the Toronto event. By coming together, we amplify our collective impact and strengthen the voices of our communities, while ensuring that funds raised by each organization directly support their respective missions.

**Be part of this powerful movement. Register today at [www.freedomtomove.org](http://www.freedomtomove.org) and help us raise \$60,000 to drive dystonia research and support.**

## Virtual Event

**When:** June 1 – 30, 2026  
**Location:** Anywhere in Canada  
**Early Bird Pricing:** \$10/Adult;  
 Free for Children

## Toronto In-Person

**When:** June 14th  
**Where:** Downsview Park  
**Early Bird Pricing:** \$30/Adult;  
 \$10/Child

**Don't Wait,  
 Register Today!**



**Early Bird Deadline - Register by May 14th to Save 50%**



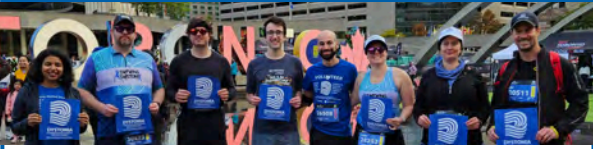
## Dwayne Backer Memorial Award for Excellence in Fundraising

In 2022, the dystonia community lost a passionate advocate, Dwayne Backer. A dedicated supporter of DMRF Canada and long-time Freedom to Move participant, Dwayne raised nearly \$120,000 for dystonia research and support programs over two decades, and continues to give through his legacy gift.

Established in his memory, the Dwayne Backer Memorial Award for Excellence in Fundraising recognizes the top individual fundraiser for this year's event and continues to honour Dwayne's remarkable commitment to the dystonia community.

# How Your Support Makes a Difference:

## Impact Today



### Medical Education and Training

We invest in advanced medical education and training to strengthen physicians' ability to diagnose and treat dystonia, deliver treatments more precisely and effectively, and ensure research discoveries translate into better care and faster outcomes across Canada.

### Support and Education Programs

Support requests have risen by more than 45% compared to previous years. Your generosity helps DMRF Canada provide essential support and trusted resources to the dystonia community. Through education, peer connection, and practical resources—including expert-led webinars, support meetings, newsletters, and materials for those newly diagnosed—individuals and families receive reliable guidance and reassurance at every stage of living with dystonia.

## Impact for the Future



### Clinical and Research Fellowships

65% of our 2025 *Dystonia Canada Survey* respondents said they would like better access to services or specialists. Your support directly responds to this urgent need.

Across Canada, there are fewer than 80 movement disorder specialists, according to a Parkinson Canada report. Your support helps train highly skilled movement disorder specialists and builds much needed national capacity. By investing in specialist training today, you are helping improve care for people living with dystonia tomorrow. Made possible by community support this year, Canadian physicians training to specialize in dystonia include pediatric physician Dr. Lindsey Vogt (Toronto) and adult physician Dr. Blanche Perraud (London, UK).

### Critical Dystonia Research Projects

Funds raised support important dystonia research, including studies on deep brain stimulation (DBS), non-invasive stimulation methods, better diagnostic tools, and research to better understand the underlying causes of dystonia in children and adults.

*Together, these efforts address urgent needs today while improving quality of life and accelerating progress toward better diagnosis, treatments, and care.*



## People Give to People, Not Causes - Be the Voice that Fuels the Cure.

Beyond raising critical funds, Freedom to Move is also a powerful opportunity to increase awareness about dystonia. One of the most common ways people discover DMRF Canada, or choose to donate, is through someone they

know personally. **In fact, people are at least twice as likely to give when asked by a friend or family member than when approached directly by a charity.**

Reaching out to your network can feel intimidating, but you don't have to do it alone. That is why we created the [Freedom to Move Fundraiser's Toolkit](#), designed to help you break the ice and build confidence as you grow your fundraising impact. The Toolkit includes sample emails, social media posts, pledge sheets, an infographic showing how donations make a difference, and practical tips to keep your momentum going. It's everything you need to support your fundraising journey from start to finish.

## Community Voices

"Thank you so much for all of these links for information and resources. I am very happy to have joined up and to finally be part of the dystonia community and hopefully not feel as alone learning to live with this."

- *New community member who recently subscribed to our newsletter.*



# Freedom to Move Ambassador 2026: Meet Laurence Gu nette-Rochon

For Laurence Gu nette-Rochon of Quebec City, Freedom to Move is about connection, resilience, and hope. At just 27 years old, Laurence is navigating life with cervical dystonia and using her voice to remind others that they are not alone.

Laurence's journey with dystonia began in the fall of 2022 with a subtle but unsettling sense that something was not quite right. "At first, it was just a general sense of discomfort. I didn't quite know how to describe it; I just kept saying that my neck felt 'funny.'"

Despite months of physiotherapy, her symptoms gradually worsened. Nearly 18 months after those first signs, following a referral to a neurologist and a series of tests, Laurence received an official diagnosis of cervical dystonia.

While the diagnosis brought clarity, it also marked a turning point. The long diagnostic process, though difficult, gave Laurence and her family time to prepare for what lay ahead. "By the time the diagnosis came, we were already in solution mode. The shock was behind us, and we were ready to take the next step."

Determined to connect with others who truly understood her experience, Laurence and her family travelled from Quebec City to Toronto to attend DMRF Canada's in-person event in 2025. It was an important moment of connection and affirmation, reinforcing that community matters.

Her decision to participate in Freedom to Move was driven by a desire to break the isolation she felt after diagnosis. What she found was understanding, shared experience, and renewed optimism. "What I was really looking for was a little bit of hope, and I was not disappointed."

Looking ahead, Laurence hopes to manage her symptoms effectively so she can return to work and lead an independent life. She also remains hopeful that ongoing research will lead to better treatments, and ultimately, to a future where dystonia can be cured.

By registering for Freedom to Move, you are standing alongside ambassadors like Laurence. Every step taken and every dollar raised helps fund research and support programs, bringing us closer to a future where no one has to face dystonia alone.



## Shortening the Path to Cervical Dystonia Diagnosis

Are you or someone you know struggling to talk to health professionals about dystonia? We're here to help you gather your thoughts. In partnership with Patient Voice and AbbVie Canada, a downloadable guide to cervical dystonia remains available on the Patient Voice website, serving as an approachable tool in guiding the conversation.

Cervical dystonia is the most common form of focal dystonia. In some cases, it can take up to 10 years for a proper diagnosis. Our goal is to support Canadians in expediting their pathway to proper diagnosis and care.

## LEARN MORE ABOUT CERVICAL DYSTONIA

Dystonia is a neurological disorder that can take several years to diagnose. Its similarity to other movement disorders, combined with its wide variety of symptoms, often leads to misdiagnoses and delays.

Without an accurate diagnosis and treatment, individuals affected by cervical dystonia may live with symptoms that affect their daily life.

CERVICAL  
DYSTONIA  
IS THE MOST  
COMMON FORM  
OF DYSTONIA.

This guide was developed in collaboration with neurologist Dr. Anne-Louise Lafontaine as a tool to help you talk to your family doctor about cervical dystonia.



This valuable guide can be accessed by visiting [www.patientvoice.io/dystonia](http://www.patientvoice.io/dystonia).

*Cervical dystonia is a specific form of dystonia that affects the head and neck. Cervical dystonia produces excessive muscle contractions in the neck. These muscle contractions cause involuntary movements and awkward and sometimes painful positions of the head, neck, and sometimes shoulders. Cervical dystonia is among the most common forms of dystonia and is sometimes referred to as spasmodic torticollis.*

“The time to diagnosis for cervical dystonia can vary widely,” explained Scott Norris, MD, Associate Professor of Neurology at Washington University in St. Louis and former DMRF clinical fellow and member of the Medical and Scientific Advisory Council. “Some individuals may receive a diagnosis within months, while for others, it may take years. The time to diagnosis can depend on factors such as the individual’s access to specialized medical care and the awareness of dystonia among healthcare providers for whom they engage with. Often, it is upwards of somewhere between one to five years to receive a proper diagnosis.”

Dr. Norris added that cervical dystonia is sometimes mistaken for other conditions such as musculoskeletal disorders, stiff neck, traumatic neck injury, arthritis, essential tremor, Parkinson’s disease, stress or psychological distress, or other neurological disorders.

### What are the Symptoms of Cervical Dystonia?

Cervical dystonia may cause sustained head postures, and/or abrupt, jerking head and neck movements. Many individuals have a combination of sustained and jerky movements. Jerky movements may resemble a tremor, and sometimes dystonia may be confused with essential tremor. The severity of the condition can vary widely.

Cervical dystonia may cause the:

- Neck to twist or tilt to the side
- Head to tip forward or back
- Shoulder to elevate toward the ear
- Neck to shift away from the midline of the body

Up to 75% of people with cervical dystonia experience pain in the neck and shoulder area. Headaches are also frequently reported. It is not unusual for individuals with cervical dystonia to have hand tremors.

Non-movement symptoms may include depression and anxiety disorders.

“Pain is not always a part of cervical dystonia but is often reported in up to 75% of affected patients and can severely impact quality of life,” said Dr. Norris. “Pain can relate to muscle spasms and abnormal postures, and occasionally nerve injury. Pain may result from sustained muscle contractions of neck muscles affecting surrounding body regions, compensatory postures to alleviate discomfort that places stress on other body parts, or possibly abnormal brain pathways that enhance pain sensitivity.”

### Treatments for Cervical Dystonia

The most effective treatments for cervical dystonia include:

1. Botulinum toxin injections (Botox, Dysport, Xeomin): These remain the first-line treatment due to their efficacy in reducing muscle spasms and pain.
2. Oral medications: Anticholinergic drugs, muscle relaxants, and pain medication.
3. Physical therapy: Supports muscle conditioning and pain management.
4. Deep brain stimulation (DBS): This surgical option can be considered in severe cases unresponsive to other treatments.

In the last 5–10 years, research has focused on refining botulinum toxin application, improving DBS techniques, and exploring genetic and molecular targets for dystonia.

### What Type of Doctor Treats Cervical Dystonia?

In addition to neurologists with special training in movement disorders, many dystonia patients get treatment from physiatrists, who are medical doctors specializing in physical medicine and rehabilitation (PM&R). Certain doctors of osteopathic medicine (DO)

*Article continues on page 10*

and otolaryngologists (ENT) may also have expertise in treating cervical dystonia, depending on their training and experience.

### Does Cervical Dystonia Progress?

Symptoms usually plateau and remain stable within a few years of onset. The symptoms, however, may continue to change or fluctuate in severity over time. In

approximately one-third of people with cervical dystonia, the symptoms spread to nearby body areas such as the face, jaw, shoulder, and/or arm.

Cervical dystonia symptoms are often partially relieved by a “sensory trick” (also known as a geste antagoniste) such as gently placing a hand on the chin, other areas of the face, or back of the head. A person with isolated (primary) cervical dystonia is more likely to respond to a sensory trick than someone with acquired (secondary) cervical dystonia.

### Living with Cervical Dystonia

The early stages of onset, diagnosis, and seeking effective treatment for cervical dystonia are often the most challenging. The symptoms may vary from mild to severe, and symptoms often fluctuate from day to day. Cervical dystonia often causes significant physical pain and fatigue. Individuals may have to learn new ways to accomplish daily tasks. Individuals diagnosed with dystonia can experience non-motor symptoms such as disruptions in sleep, anxiety, depression, or pain-related symptoms that affect more than how the body moves.

Individuals living with dystonia are strongly encouraged to:

- Seek out the best medical care.
- Educate yourself about dystonia and treatment options.
- Develop a multi-layered support system of support groups, online resources, friends, and family.
- Seek expert mental health professionals to diagnose and treat possible co-existing depression or anxiety disorders.
- Investigate complementary therapies.
- Get active within the dystonia community.

Source: Cervical Dystonia | Dystonia Medical Research Foundation  
<https://dystonia-foundation.org/what-is-dystonia/types-dystonia/cervical-dystonia/>

*Adapted and reprinted with permission from DMRF Dystonia Dialogue Summer 2025 Vol 48. No 2*

## OFF BALANCE: The Hidden Risks of Cervical Dystonia

*Why neck spasms could mean more than just pain*

People with cervical dystonia (CD) often struggle with uncontrollable neck muscle spasms that twist or tilt the head. But what many don't realize is that CD doesn't just affect appearance or comfort—it can quietly increase the risk of falling.

A new study from researchers in Brazil has found that most CD patients experience balance problems and gait disturbances, which heighten both the likelihood of falling and the fear of falling—even among those who haven't fallen before.

Using well-known balance and mobility tests, the study showed:

- Over 70% had measurable balance issues
- 60% had impaired walking ability
- More than half feared falling frequently

The findings from this single study involving a cohort of 46 patients suggest that CD affects more than just muscle control—it disrupts the body's ability to stay upright and move confidently. The fear of falling often leads patients to reduce their physical activity, which can further weaken their muscles and worsen balance.

**Takeaway:** If you or someone you know has cervical dystonia, talk to a healthcare provider not only about treating muscle symptoms but also about fall prevention strategies, balance training, and physical therapy.

Source: Do patients with cervical dystonia present a greater risk and more fear of falling? Arquivos de Neuro-Psiquiatria Vol. 83 No. 3/2025 © 2025.

<https://www.arquivosdeneuropsiquiatria.org/article/do-patients-with-cervical-dystonia-present-a-greater-risk-and-more-fear-of-falling/>

# What to Expect from Botulinum Neurotoxin Injections

*Botulinum neurotoxin injections are a common dystonia treatment, first used for blepharospasm 30 years ago. This is a highly specialized, ongoing therapy that must be customized to each patient. There are several factors that can influence the outcome for treatment, degree of benefit, and chance of side effects. It is also important to manage expectations before starting any new treatment protocol.*



Mark S. LeDoux, MD, PhD, a clinician-scientist from Veracity Neuroscience in Memphis, TN, noted that the skill of the injecting physician is the most critical factor in clinical outcomes, even more than the amount of toxin injected.

“Skilled injectors will often have a very good idea of how many units of toxin are necessary and what muscles to target,” Dr. LeDoux explained. “Injection skill is very important for treating writer’s cramp, blepharospasm and particularly laryngeal dystonia... There are many people who do injections but very few that are skillful enough to obtain optimal results on a consistent basis.”

Dr. LeDoux believes that injections that are EMG guided will be most effective, especially for arm dystonia, leg dystonia, cervical dystonia, and laryngeal dystonia. EMG guidance is rarely required for blepharospasm. EMG guidance is a technique that uses electromyography signals to help healthcare providers accurately locate and inject needles into specific muscles for medical treatments. The system provides real-time audio and visual feedback, indicating when the needle has entered an active muscle, allowing for more precise delivery and potentially improving treatment outcomes by ensuring the toxin is delivered to the correct, affected muscle group.

For patients who are new to receiving botulinum toxin treatments, here are a few things to keep in mind:

- **Getting to the Correct Dosage Takes Time:** Doctors typically start with a smaller dosage of botulinum toxin and emphasize to the patient that an increased dose may be needed at future visits. Achieving the optimal dosage is a collaborative effort between the patient and physician, so patients should keep a record of the dosage amount where they started to notice any symptom improvements.

- **Do Not Expect 100% Improvement:** Even with injections performed by a skilled and highly experienced injector, results may still be suboptimal. Patients should expect an improvement in the severity of their dystonia when injected correctly, but it is unrealistic to expect the symptoms to disappear completely.
- **Be Aware of Potential Side Effects:** These may include neurovascular injury, infection, bruising, bleeding, excessive weakness, flu-like symptoms and other allergic responses, which are rare. Slight bruising is the most common potential side effect and usually resolves within five to ten days. Injections for cervical dystonia may cause some patients to develop head drop or dysphagia (difficulty swallowing).
- **Injections Involve Multiple Sites:** In general, there are two to three injection sites per muscle. For most patients with cervical dystonia at least three muscles will be injected. Other dystonia patients with leg or arm involvement may have more than five muscles injected, which means many patients will get 12 or more injections during one treatment session. Clinicians use either a 30-gauge or 27-gauge needle—the bigger the number the thinner the needle.
- **Ask About Options to Lessen Needle Anxiety:** Pediatric patients may benefit from a shot blocker (also called a shot pain reducer), which is a non-invasive device shaped like a small disc placed over the injection site that distracts patients from needle poke pain signals. Patients with significant anxiety may benefit from taking a benzodiazepine (such as alprazolam) one hour prior to injections.

*Article continues on page 12*

- **Educate yourself regarding cost coverage:** Check your provincial healthcare and extended benefits to find out what the requirements are for cost coverage of botulinum toxin injections. Your doctor's office or movement disorders clinic may be a good starting point to find more information on provincial coverage policies. Your extended benefits may require preapproval.

Additional training for physicians who administer botulinum toxin injections ultimately benefits dystonia patients. "Training is highly variable among different training programs," Dr. LeDoux explained. "At many academic institutions, injections for blepharospasm may be performed by an ophthalmologist and injections for laryngeal dystonia may be performed by a laryngologist. There are very few neurologists who inject neurotoxins for all forms of dystonia."

As a proactive patient, or the parent or caregiver of a dystonia patient, you have a right to fully understand all treatment options and any potential side effects associated with your choices. Knowing what to expect before treatment begins is an important part of taking control of your care.

*Adapted and reprinted with permission from DMRF Dystonia Dialogue, Winter 2025 Vol 48, No 3.*

## Neuromodulation in Dystonia Meeting Held in Atlanta



Neuromodulation is a broad category of treatment that includes non-invasive and invasive methods, like Deep Brain Stimulation (DBS), aimed at reducing muscle spasms and contractions by using mild electrical pulses to alter nerve activity in the brain or nervous system. On November 13-14, 2025, DMRF USA hosted a meeting on "Neuromodulation in Dystonia" in Atlanta, gathering experts across disciplines in this field.

The meeting was chaired by Noreen Bukhari-Parlakturk, MD, PhD, Assistant Professor of Neurology at Duke University Health in Chapel Hill, NC, and Michael D. Fox, MD, PhD, Director, Center for Brain Circuit Therapeutics, at Brigham and Women's Hospital in Boston, MA. Session topics included Fundamental Insights into Neuromodulation Targets for Dystonia, Network Level Effects of Brain Stimulation in Dystonia and Translational Insights from Clinical Trials in Dystonia.

We are grateful Dr. Jean-Francois Nankoo from Toronto Western Hospital was able to attend this meeting. He shared that, "The workshop was the most productive, engaging and insightful meeting I have been to. I learned a lot from experts in different fields, and we will likely establish new collaborations as a direct result of this workshop."

Our thanks to the DMRF USA for allowing us to republish this information.

*We gratefully acknowledge Ipsen Canada for their generous grant, which facilitates synergizing efforts in collaborative research.*



To read more about the scientific meetings and educational programs DMRF Canada has supported, please visit: [www.dystoniacanada.org/scienceandresearch](http://www.dystoniacanada.org/scienceandresearch)

# Community Education and Impact

## DMRF Canada is Built and Sustained by Volunteers

Read on to see our recent successes, current opportunities and upcoming needs.

### Find Your Community

Join one of our upcoming online support group meetings, run by our volunteer leaders. Connect with a like-minded community, share resources and draw support from others focused on living well with dystonia. Groups are open to those living with dystonia and those who support them.

- Winnipeg, MB Virtual Meetings Last Saturday of each month
- Thompson/Okanagan, BC Virtual Meeting Monthly on the 7th
- Vancouver Island, BC Virtual Meeting Monthly on the 21st
- National Virtual Support Meetings on May 16th, September 12th, and November 21st
- Greater Toronto Support Group Virtual Meeting on July 26th



Contact information for support groups across the country can be found on the Resources tab of our website. For the most up-to-date information on upcoming meetings, visit: [www.dystoniacanada.org/upcoming-events](http://www.dystoniacanada.org/upcoming-events)



### Seeking Support Group Leaders

Building connections in local communities is one of the most effective ways to improve dystonia support and awareness. Help DMRF Canada make an impact by becoming a local support group leader. We are currently looking for volunteer leaders in:

- Victoria, BC (Co-Leader)
- Edmonton, AB (Co-leader)
- Saskatoon, SK
- Fredericton, NB

If you are interested, please email us [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

### Community Voices

After attending one of the National Virtual Support Meetings, Helen Dyks from Kingston, Ontario became a peer support contact in her region. She has since begun distributing dystonia educational materials to her movement disorder specialist, helping expand awareness and support for people living with dystonia in her local community.

Helen shared:

“Thank you for including me in the virtual discussion a few weeks ago. The experience was both deeply informative and profoundly moving. Hearing others’ stories offered valuable perspective on my own journey. The session was excellently facilitated, with full engagement from all participants.”

Stories like Helen’s show how joining a support meeting can be a meaningful first step in connecting with others and strengthening our community. If you have been thinking about attending but are unsure where to start, we encourage you to join a meeting and break the ice. You may also discover opportunities to support others by becoming a peer support contact in your region.



# Community Education and Impact

## Alberta Casino Fundraiser Update

Alberta's charitable gaming model allows charitable organizations, such as dystonia support groups, to conduct and manage casino events for a portion of the gaming proceeds. These events require an incredible volunteer effort. Over two days, members fill approximately 40 volunteer shifts — many running late into the night and early morning hours.

Each volunteer shift can generate up to \$2,000 for dystonia support, meaning that together, these efforts can help fund an entirely new research project.

Edmonton's group completed their casino fundraiser in August 2025 and Calgary's group, in January 2026. A heartfelt thank you to the dedicated members who volunteered their time and reached out to their networks for support. Your commitment and generosity make these events — and the research they support — possible.



## Call-out for new Casino Chair in Edmonton AB

The Casino Chairperson is a leadership opportunity for someone who wants to make an impact behind the scenes. This role oversees the planning and compliance of casino fundraising events providing essential funding for dystonia research, education, and support programs. If you are interested, please email [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

## Education Initiatives Raise Awareness and Knowledge of Dystonia

### Learn From Experts: Dystonia Sessions Online

The efforts of the Alberta dystonia support groups are continuing to give back to our community. The Alberta Dystonia Symposium successfully hosted over 50 attendees in Red Deer to learn, engage and connect in September 2025. The following sessions, led by experts in the field, were recorded and are now available for viewing:

- "Deep Brain Stimulation (DBS) and Other Treatment Approaches" presented by Dr. Aakash Shetty of the University of Alberta
- "Patient Awareness and Pathways to Diagnosis and Treatment", presented by Dr. Davide Martino of the University of Calgary
- "Brain Training for Dystonia" presented by Jacquie Townsend, BMR PT, Physiotherapist, Alberta Neurologic Centre



To watch these and other recording from past webinars or informational sessions, please visit our website: [www.dystoniacanada.org/dystonia-information-sessions](http://www.dystoniacanada.org/dystonia-information-sessions)



## Community Voices

"I wanted to thank you for the work you do and the resources you've created. Your YouTube seminars have been incredibly helpful in making me feel more confident and comfortable before going in (Dr. Dung Nguyen's talk on navigating movement specialist visits was especially useful). Having these videos available has made a huge difference, and I'm thrilled to pursue treatment with informed opinions now."

- New community member who recently subscribed to our newsletter.



# Community Education and Impact

## Ontario Bingo Volunteers Urgently Needed

We are excited to announce that DMRF Canada has successfully secured a new fundraising opportunity at Delta Bingo in Etobicoke, Ontario. Our partnerships with Bingo World and Gaming in Richmond Hill and Delta Bingo in Etobicoke have raised over \$100,000 since July 2024, thanks to dedicated volunteers. We urgently need more volunteers to sustain this critical funding. Just a two-hour shift per month helps keep the program running. Without enough volunteers, this essential support is at risk.

Funds raised directly support people living with dystonia by funding clinical and research fellowships at Toronto Western Hospital and SickKids, and by sustaining DMRF Canada's education, peer support, and practical resource programs. If you are in the Greater Toronto Area, please consider volunteering or sharing this opportunity. No experience is required, only a monthly commitment.



To learn more and view upcoming dates, visit [www.dystoniacanada.org/ontariobingo](http://www.dystoniacanada.org/ontariobingo)



## Volunteer Spotlight: Stephen Rogow



Stephen Rogow is one of the dedicated volunteers supporting DMRF Canada through the bingo fundraising program.

**Through his ongoing commitment, Stephen has helped raise over \$50,000 for the Foundation** — an incredible contribution to the dystonia community.



Stephen describes the experience as both simple and meaningful. “I can honestly say it is one of the simplest and most rewarding ways to give back,” he says.

For Stephen, volunteering is about more than fundraising. It's also an opportunity to raise awareness about dystonia and the work of the Foundation. “As volunteers, we act as ambassadors for DMRF Canada,” he explains. “Even small conversations can help people learn about dystonia and the support that's available.”

Stephen also reassures potential volunteers that there is no pressure to have all the answers. “We're not expected to know everything,” he says. “If a question comes up that we can't answer, we simply connect the patron with a hall staff member who can help.”

He also values the connections made along the way. “It's a great way to connect with other dystonia volunteers, share stories, and be part of something bigger than yourself.”

Stephen hopes others will consider getting involved. “Even small moments of helping can make a difference,” he says. “Your presence matters.”

## Connecting Canadians with Dystonia-Informed Physiotherapists



Not all health professionals are experienced in neurological movement disorders. One of the most common requests we receive from the dystonia community is help connecting with physiotherapists who understand and treat people living with dystonia.



To support this need, we have compiled a list of physiotherapists across Canada who have experience working with dystonia patients. [www.dystoniacanada.org/physiotherapy-and-dystonia](http://www.dystoniacanada.org/physiotherapy-and-dystonia)

It's important to us that this resource remains comprehensive and up to date. If you would like to be added to the list, or would like to recommend a physiotherapist who should be included, please contact us at [info@dystoniacanada.org](mailto:info@dystoniacanada.org).

# From Symptoms to Solutions: The Importance of Discussing Non-Motor Symptoms (NMS) with Your Physician



Dystonia is recognized as a complex motor disorder. It can present at any age, with varying levels of severity, affecting single or multiple parts of the body. What isn't well recognized is the treatment of non-motor symptoms (NMS) and the role they play in quality of life for those with dystonia. Sometimes these NMS have an even greater impact on quality of life than the motor symptoms themselves. The complexity in presentation and symptoms of dystonia is not yet well reflected in how we treat it.

“Our current model of care for dystonia is predominantly directed at the motor features of adult-onset dystonia,” explains neurologist, Dr. Kyna Squarey. As the movement disorders specialist serving

Newfoundland and Labrador, Dr. Squarey sees mostly patients with Parkinson's or dystonia. Much of her practice is specialized in treatment with Botulinum Neurotoxin Toxin (BoNT). While BoNT is effective for many, it is not the only answer. Dr. Squarey is constantly thinking about how she can provide more holistic care for dystonia in a system that does not prioritize this approach. “We need to be doing more than quick BoNT clinics for these patients but there isn't time in that appointment to screen, assess and actively manage the non-motor symptoms.”

## What are non-motor symptoms (NMS) of dystonia?

Those living with dystonia are well aware of the motor symptoms. The muscle contractions, spasms, cramping, stiffness and tremors define the disorder. NMS associated with dystonia can include pain, anxiety, depression, sleep disturbance, obsessive compulsive disorder, social phobia, poor self-esteem and negative body image. Cognitive disorders specifically in the area of executive functioning also commonly co-occur with dystonia. Executive functioning encompasses skills such as attention, memory, organization and planning. People with difficulties in these areas may have trouble with everyday tasks like being on time, following a recipe, planning their day or remembering something they have read.

While some NMS can be considered secondary to the effects of the motor symptoms or medication, there is research that suggests a higher occurrence of certain NMS in dystonia than even in other movement

disorders. Research is limited and inconclusive, but the issue remains that these have a great impact on the lives of those living with them.

## How are non-motor symptoms currently treated?

Dr. Squarey notes the most consistently addressed NMS is pain. BoNT injections are aimed at decreasing muscle activity causing painful contractions and spasms. When it comes to most other NMS, they are typically managed by primary care physicians. “They're the ones managing the anxiety, depression, sleep problems, fatigue and cognitive dysfunction,” explains Dr. Squarey. “The non-motor symptoms are still really under-recognized by both specialist neurologists and general neurologists. Patients are passively accepting that they have these things and not relating it to their dystonia.”

She emphasizes this lack of recognition means that only some of the patient's symptoms are being treated, providing results that don't target all areas of need and can lead to an overall dissatisfaction with care. In short, current treatment of NMS is often separate and apart from dystonia treatment which isn't capturing the whole picture. “There's a real need for new approaches and treatment pathways in dystonia. We need an updated model of care.”



*Dr. Kyna Squarey is a movement disorder specialist in Newfoundland who strives to ensure her patients' non-motor symptoms of dystonia are acknowledged so they can be addressed in treatment.*

Article continues on page 17

### Reimagining dystonia care to include treatment for non-motor symptoms

Dr. Squarey has observed that a better model of care can exist. In her experience, patients at a Parkinson's clinic have the opportunity to consult with many professionals who have specialized knowledge of movement disorders. "For example, you could see a nurse, a physiotherapist and an occupational therapist," Dr. Squarey says. "They're multidisciplinary." She would love to see a model that includes this in dystonia care, as opposed to a standard "ten-minute BoNT appointment." She's able to incorporate some of this into practice in her clinic where she has access to massage therapists, physiotherapists and counsellors to consult or refer to. She notes that with the way the medical system is set up, only physician care is covered. This makes it hard to establish a model outside of a publicly funded facility, like a hospital, with adequate multidisciplinary care due to a lack of funding.

She also calls for more attention to research in developing a tool for better assessment of non-motor symptoms. A questionnaire exists but it simply answers whether symptoms are present and does not provide information as to how much of an impact they are having on a person's overall health so that treatment of certain symptoms can be prioritized.

### Practical tips for now

Overhauling the model of care is a long-term goal. In the meantime, there are steps patients can take to address their NMS and move towards more holistic care for dystonia.

- 1. Acknowledge and learn about the non-motor symptoms of dystonia:** Because motor and NMS haven't historically been addressed together, patients don't explore treatment of both. "As physicians we need to be asking about the non-motor symptoms and patients need to be bringing them to us," emphasizes Dr. Squarey. It's that partnership of responsibility that can yield more efficient results in addressing all symptoms of dystonia.
- 2. Investigate non pharmacological options for pain with allied health professionals:** If you're able to access expertise from professionals such as occupational therapists, massage therapists, physiotherapists and speech-language pathologists, they can guide you towards exercise and adaptations that can help manage pain. "There are things like sensory tricks, or use of heat and cold that can be effective," advises Dr. Squarey.

- 3. Seek psychological support:** Many non-motor symptoms can be addressed with the help of psychological health professionals. Cognitive concerns like executive dysfunction can be assessed by a neuropsychologist to understand which areas require support. Psychologists or counsellors address anxiety, depression, body image and self-esteem. Even more, effective stress management plays a role in alleviating motor and non-motor symptom. "Learning mindfulness and relaxation techniques," explains Dr. Squarey, "Can help decrease stress which we know can exacerbate muscle tension." Not all of these will be effective for everyone but finding the right professional guidance can lead you more quickly to solutions tailored specifically to you.
- 4. Don't discount lifestyle changes:** Just because something isn't pharmacological, it doesn't mean that it is not effective treatment. NMS can be responsive to shifts in daily routines and habits. Remaining physically active, working to stay socially engaged and developing a sleep routine are just some of the lifestyle factors that can significantly improve outcomes for NMS. DMRF Canada strives to make information about these available to members of the community as well as promoting social connections through support groups across the country.

Because treatment for non-motor symptoms is not attached to the current model of dystonia care in many parts of Canada, it can feel overwhelming to find, access and coordinate these options. Dr. Squarey encourages patients to acknowledge symptoms as part of their dystonia diagnosis, start small and try one thing. "Patients are often trying to fight or hide their [motor and non-motor] symptoms, but that can actually make things worse." By becoming more aware that NMS are part of the whole picture, you can better discuss the impacts of dystonia with your doctor and seek options for a more holistic course of treatment.



To learn more about the non-motor symptoms of dystonia and available support resources, please visit: [www.dystoniacanada.org/nonmotor](http://www.dystoniacanada.org/nonmotor)

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This article is supported by AbbVie Canada



## From Lived Experience to Leadership: How Julie Trant and Lance Howitt are advancing dystonia research and awareness



Husband and wife, Lance Howitt and Julie Trant, spent a lot of years not talking about dystonia. Julie (whose story you may have seen featured in last year's mailout fundraising campaign), was diagnosed as a child, but found ways to cope with and hide her symptoms. It wasn't until one of their sons received his diagnosis of dystonia, that out of necessity, they really started talking about it. This is what brought them to DMRF Canada and prompted Lance to prioritize his involvement, spearheading individual fundraising and awareness efforts in coordination with DMRF Canada, and then formally joining the board of directors in January of 2025.

Julie and Lance first connected with DMRF Canada in 2017. Since that time, both Julie and her son have undergone successful treatment with Deep Brain Stimulation (DBS) in France, under the guidance of internationally recognized movement disorder and dystonia expert Dr. Laura Cif. While they sought treatment overseas, Lance and Julie recognized the value in having knowledge available through a Canadian entity. "Early on, DMRF Canada was very important for us because the resources helped us understand more about dystonia, the available treatment options, and to formulate all the different questions we should ask before having the surgery," Julie remembers.

After the remarkably transformational results of DBS and realizing the valuable role DMRF Canada played in supporting their family during a difficult time, Julie and Lance set to work partnering with the foundation to bring awareness and raise funds for dystonia research. They have prioritized donating financially, but Lance began to recognize they may have more to

contribute. "Money is only one resource. It's really about time, expertise and a network," Lance says. "In many respects, those resources are a lot more scarce - and therefore valuable - than just the dollars."

It's those intangibles that Lance brings to his position on the board. As an accomplished serial entrepreneur and early adopter of technology, Lance has found success in business. "My accomplishments are not a result of formal education. It's just having the strategic vision and internal courage to get out there and get it done," he explains. "Having focus on gaps and opportunities in industry for many years, I intuitively understand many of the issues people face in their organizations. I'm always trying to connect people with constructive ideas to solve problems and move forward. Finding that nexus is what I've done successfully for 30 years. Through my philanthropic role on the board of DMRF Canada I hope to augment our family's financial contributions with greater influence and success."

Lance and Julie hold research as a high priority when it comes to the impact they would like to make in the world of dystonia. The positive impact of research and modern medicine on Julie's and her son's quality of life has been immeasurable. When asked what he will look at as a mark of success for his time on the Board of Directors, Lance has his family's experience in mind. "If we can find any kind of research breakthrough in diagnostics, treatment or prevention that will be very important progress," he says. His background in big picture thinking and value on connection gives him some innovative ideas as to how this can be done. Commenting specifically about the leverage AI technology has for medical research and the multi-centre project led by Dr. Cif, Lance says, "If we can create more of an interwoven community between the Canadian medical community and expert researchers from around the world, there's a key role that our people, our contribution and our country of Canada can play."

*Article continues on page 19*



DMRF Canada has a long history of knowledge sharing with researchers and medical professionals from around the world. They hope that further interconnecting Canadian initiatives with what is happening globally can have an impact at the local level. Lance has observed, “By population Canada is a relatively small country and DMRF Canada, works on a pretty limited budget, which inherently limits opportunity and to some degree awareness as well. Dystonia is not a well-known disorder, so it doesn't attract a ton of attention.” By getting louder about their family’s experiences with dystonia, they are using their voices to raise awareness. Julie has been generous in sharing her lived experience to provide information and hope to others. She has noted how important it is that the broader community helps to “get the word out to more people” to improve the level of understanding about dystonia. This is a role they both embrace. “I'm just trying to see if I can get creative and help spread the message- an awareness message, and a message of hope,” says Lance.



With research and awareness at the top of their list, Lance and Julie are making great contributions towards a future with a cure for dystonia. By leveraging local Canadian infrastructure and the DMRF Canada to connect and integrate even more with the world of global research and innovation, Lance and Julie are providing hope and a necessary push to think big. “A cure can just come from one person, one idea, one innovation, one moment in time, one place in the world. It could happen here in Canada.” Lance says.

At DMRF Canada we share Lance and Julie’s hope for the future. It’s because of commitment from members of our community like them, that we can move forward with our goals.

## Canadian Movement Disorders Organizations Join Together to Train the Next Generation of Specialists — A New Collaborative Initiative



Parkinson Canada, Dystonia Medical Research Foundation Canada, and the Huntington Society of Canada are pleased to launch the Clinical Movement Disorders Fellowship Program. This collaborative initiative represents an alliance among Canada's leading movement disorder organizations, working together to address the critical shortage of specialized clinicians trained in the comprehensive care of complex neurological conditions.

Through this collaboration, the partners will co-fund a clinical fellowship in 2026-2027, with an award of \$80,000 supporting an exceptional candidate pursuing specialized training in movement disorders. We are pleased to jointly award this fellowship to Blanche Perraud, who will train at one of the leading movement disorder institutions.

“Collaborations like this are especially important for smaller communities such as dystonia,” says Archana Castelino, National Director of the Dystonia Medical

Research Foundation (DMRF) Canada. “Together, we are expanding training opportunities for future specialists in movement disorders and saving valuable time and other resources for fellows and host institutions. As DMRF Canada marks 50 years of advancing care and research for dystonia, we remain committed to continuing this work alongside our partners.”

This partnership reflects a growing recognition that movement disorders share common features, challenges, and care needs. By working together, the three organizations can maximize their impact while reducing duplication of efforts to benefit all Canadians affected by movement disorders.

For more information, visit:

[www.dystoniacanada.org/news/canadian-movement-disorders-organizations-join-together-train-next-generation-specialists](http://www.dystoniacanada.org/news/canadian-movement-disorders-organizations-join-together-train-next-generation-specialists)



## A Life of Connection: Laraine Orthlieb's Commitment to Community

As with many volunteers within our community, the lives they lead before stepping into advocacy often shape how and why they give back. In the case of retired Commodore Laraine Orthlieb, her lifelong commitment to building and sustaining community has guided every chapter of her life, including her years co-leading Calgary's Dystonia Support Group from 2017 to 2023.

Orthlieb is well known in Canada for being the Navy's first female Flag Officer. A quick internet search reveals a list of Orthlieb's accolades and attributes: determination, tenacity, leadership, pioneering vision...but behind each achievement is a consistent focus on people and connection.

Her Naval Reserve career spanned 23 years. She began as a nursing officer and then became a Naval Control of Shipping Officer. She served as a Commanding Officer and then was selected for several foreign postings in places like Italy and Brussels. Along the way she pushed boundaries and opened doors for women that came after her. This earned her recognition as the namesake of the Commodore Laraine Orthlieb Naval Training Centre in Calgary. She continued to give back after her formal service, playing a vital role in the establishment of the Naval Museum of Alberta.



Commodore (retired) Laraine Orthlieb has spent part of her retirement giving back to the dystonia community through the Calgary Support Group

What stayed with Orthlieb most, however, were the relationships formed along the way. "It's interesting how long community stays with you," she reflects. When the Naval Training Centre was dedicated in her name, she looked out at the audience and recognized many faces. "I thought, wow, some of these people I met over 25 years ago, and they've turned up," she marvels. It was an early reminder that the communities she helped build endured long after the work itself was done.

That understanding deepened after her Navy career when Orthlieb and her husband Robert, moved to Bolivia where he had a job with Petro Canada. "They initially really wanted my husband. He grew up speaking Spanish and is an engineer," she explains. Orthlieb wasn't sure where she would fit in. It didn't take long for her leadership skills and her instinct for connection to prove invaluable in her new environment.

She noticed a high turnover among families sent abroad for work. "I realized these people were coming home because, what about their families?" she explains. She decided to speak directly to these families and found the issue wasn't the job. It was the lack of community support. Orthlieb brought her observations to Petro Canada, proposing solutions centered on caring for families as well as employees. The result? They hired her too. What began as a short contract turned into a four-year stay, once again rooted in her understanding that people thrive when they feel supported and connected.

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In 2000, Orthlieb faced a new challenge when she was diagnosed with cervical dystonia, then several years later with laryngeal dystonia. “I had a difficult time finding out anything about dystonia. You had to do your own research,” she recalls. By chance she discovered DMRF Canada online and learned there was a support group meeting in Calgary. “I showed up at the meeting,” Orthlieb remembers, “And the president at the time passed me a piece of paper and a pen and said, would you take minutes for this meeting?” Just like that, she became the secretary of the Calgary Dystonia Support Group.

During her time with the support group, Orthlieb wanted to help increase people’s access to information. As part of their meetings, she and the group invited doctors to come speak. In one memorable instance, Dr. Nicholas Strzalkowski came to speak during a time when the group was looking for volunteers for a casino fundraising event. Not one to pass up an opportunity, Orthlieb followed him to his car after the presentation and suggested that he may want to support them by taking a volunteer shift at the casino. She didn’t stop there. She convinced him to bring the request to his entire research team, resulting in a full roster of volunteers including Dr. Davide Martino and stronger ties between researchers and the dystonia community.

Orthlieb continued to co-lead the Calgary support group. They were successful in spearheading an awareness campaign where they displayed posters about dystonia in the University Medical Centre. She helped organize meetings until the COVID-19 pandemic hit in 2020. “It was very difficult because we couldn’t hold meetings in person. We lost a lot of people,” she says.

The bigger issue during this time was that, due to medical staff being tied up with pandemic-related needs, the botulinum neurotoxin clinics were not running. Orthlieb recalls many people in pain and distress because they could not get necessary treatment for dystonia. “I called [the clinic] and left a message saying, look, we need this,” She remembers. “We got a call back and they started injections again the next week.”

Even when meetings couldn’t happen, the group prioritized personal connection—calling members to check in, hosting family-inclusive picnics when possible, and ensuring caregivers and loved ones felt included. It echoed lessons Orthlieb had learned years earlier in Bolivia: strong communities support not just individuals, but the networks around them.

Now 88, Orthlieb has entered yet another chapter in life and recently moved to Parksville, BC, with her husband of 63 years. Though she’s no longer in Calgary, the communities she built remain. “It says a lot about how people learn to communicate and bond when they have a common project to get done,” she reflects. While she looks forward to exploring her new environment and being close to family she continues to stay in touch with friends and members of the Calgary Dystonia Support Group.

We are grateful for volunteers like Laraine Orthlieb, people who bring their skills and values to make our local communities stronger. “It’s great what DMRF Canada is doing from Toronto for nationwide activities, but you have to get the information out locally. It’s a different theatre,” she says, reminding us that meaningful connection with those around us is often the most lasting legacy of all.



## Your Story Matters

Join the conversation and share your dystonia story. Diagnosing, treating and living with dystonia can look different in different people. This means that by sharing your lived experience with dystonia, you could make a positive impact in the journey of others. Together, our voices can raise awareness and build stronger support and access to care for people affected by dystonia. If you have a story you would like to share, reach out to your local media or contact us at [info@dystoniacanada.org](mailto:info@dystoniacanada.org).

# FOCUS ON Acquired Dystonia

*Acquired dystonia, formerly known as secondary dystonia, is a type of dystonia that occurs due to an identifiable cause, such as brain injury from trauma or stroke, certain medications, toxins, infections, or associated medical conditions.*

The 2025 update for “Definition and Classification of Dystonia,” published in the journal *Movement Disorders* earlier this year, listed “Acquired” as one of the causes and biological mechanisms of dystonia, (referred to as the Axis of Etiology and Pathogenesis.) The consensus publication’s authors acknowledged that terms like “genetic” and “acquired” are not always mutually exclusive, because there are examples of genes that predispose an individual to dystonia but require an environmental trigger to manifest the movement disorder, such as rapid-onset dystonia-parkinsonism or some mitochondrial disorders, which are a group of genetic diseases that affect the organelles in cells that produce energy.

“Both genetic and acquired dystonias can have dystonia combined with other neurological features, though combined dystonia is more common in acquired dystonias. As we have learned more about the causes of dystonia and other neurologic disorders, it has become clear that the symptoms alone cannot determine the cause of the dystonia.” explained DMRF Chief Science Officer Jonathan W. Mink, MD, PhD. Just as acquired dystonia is the current term for what was previously referred to as secondary dystonia, most of what used to be described as primary dystonias are now categorized as having a genetic origin.

## Quick Facts About Acquired Dystonias

- Acquired dystonias result from apparent outside factors and can be attributed to a specific cause such as exposure to certain medications, toxins, infections, or stroke. Spinal cord injury, head, and peripheral injury are also recognized contributors to dystonia.
- Other examples of acquired dystonias include drug-induced dystonias and dystonias associated with cerebral palsy, cerebrovascular disease, cerebral infections and postinfectious states, stroke, encephalitis, brain tumour, and toxins.

- Acquired dystonia includes dystonia associated with a number of neurological and metabolic diseases. Many of these diseases are genetic. This category includes diseases such as corticobasal degeneration, pantothenate kinase deficiency (aka Hallorvorden-Spatz), Huntington’s disease, Wilson’s disease, Leigh’s disease, and juvenile parkinsonism.
- A number of acquired dystonias do not present as pure dystonia, but with a mixture of other neurologic features, such as parkinsonian features like slowness of movement and rigidity.
- Acquired dystonias may differ from genetic dystonias in that symptoms may not disappear during sleep.
- Treatment is highly customized to the individual and may be directed by what is known about the cause.
- Treatment may include physical therapy, oral medications, botulinum toxin injections, complementary therapy, and several types of surgery.

## Diagnosis and Treatment

Many of the ascribed causes of acquired dystonia are based on historical information or subtle characteristics of the symptoms, and have no diagnostic, radiologic, serologic, or other pathologic trademark.

Treatment for acquired dystonias that are attributed to additional neurological or metabolic disorders is usually directed by the specific requirements of that disorder.

Oral medications are often the mainstay of treatment for acquired dystonia. Although there is no single drug that helps an overwhelming number of individuals, there are several that may be of benefit. These oral medications include levodopa, trihexyphenidyl, clonazepam, and baclofen (oral and intrathecal especially for dystonia and spasticity). Medications may be taken in combination.

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**Oral medications are often the mainstay of treatment for acquired dystonia. Although there is no single drug that helps an overwhelming number of individuals, there are several that may be of benefit.**

Botulinum toxin injections may be used to treat specific body parts that may be affected, such as the neck, jaw, hands, or feet.

Several surgical techniques may be appropriate for select individuals who do not respond to medications and botulinum toxin injections. These may include ablative surgeries that remove diseased tissue such as pallidotomy (a surgical procedure that involves destroying a small part of the brain called the globus pallidus) or thalamotomy (a neurosurgical procedure that involves destroying a small area of the brain called the thalamus).

Other treatments may include intrathecal baclofen (using an implanted pump to deliver baclofen directly into the spinal fluid) and deep brain stimulation (implanting electrodes into specific areas of the brain to deliver electrical impulses). The specific characteristics of the disease or condition that is causing dystonia may preclude an individual from selecting surgical procedures for dystonia, or present alternative surgical options.

Complementary therapies may be explored, particularly physical therapy, aquatic therapy, and regular relaxation practices.

“Because the diagnosis and treatment of acquired dystonia is complex, a medical team is usually required for optimum care,” explained Dr. Mink. “This team should include a neurologist with expertise in dystonia. Other team members may include a physical medicine and rehabilitation physician (physiatrist), a physical or occupational therapist (or both), and in some cases a neurosurgeon. Because of the impact that acquired dystonia can have on one’s well-being and quality-of-life, a mental health professional may also be a valuable member of that team.”

Source: [dystonia-foundation.org/what-is-dystonia/types-dystonia/dystonias](http://dystonia-foundation.org/what-is-dystonia/types-dystonia/dystonias)

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**Give Monthly to Make a Bigger Difference**



For a small organization like DMRF Canada, funding varies from month to month. That’s why monthly giving is so powerful. Even a small, regular gift provides a steady and predictable source of support, allowing us to plan ahead, respond quickly to community needs, and make every dollar go further.

By becoming a monthly donor, you help us maximize our impact to ensure Canadians living with dystonia have access to resources, education, and care when they need it most.

Make a difference all year long.



**Become a monthly donor today.**

[www.dystoniacanada.org/why-i-give-monthly](http://www.dystoniacanada.org/why-i-give-monthly)

**Leave a Lasting Legacy for a Cure for Dystonia**



When updating your Will, consider including a gift to DMRF Canada. Just one simple sentence could help advance vital dystonia research and bring us closer to a cure. By making a planned gift, you leave a lasting mark in the lives of Canadians affected by dystonia and help ensure a future free from this condition. Join the DMRF Canada Legacy Society and make a difference that lasts for generations.



**Learn more:**

[www.dystoniacanada.org/legacy](http://www.dystoniacanada.org/legacy)

## DMRF Canada Needs Your Help - Please Give Generously



Each discovery builds toward the next – all leading to the ultimate goal of a cure for dystonia.

Your support matters. We exist, and our mission survives because of you. There are various ways to support DMRF Canada to have your impact felt today and ensure a brighter tomorrow for the 50,000 Canadians living with dystonia.

### Legacy Giving: Leave a Gift that Lives On

Did you know that May is Leave a Legacy Month in Canada? DMRF Canada established the Legacy Society to recognize those who have made a lifetime commitment in the battle against dystonia by naming DMRF Canada in their estate plans. Through the Legacy Society, you can make a commitment of support today to ensure the continuation of dystonia research in the future.

**Options Include:** • Wills and Bequests • Life Income Gifts: Charitable Trusts and Gift Annuities • Qualified Retirement Plans • Real Estate

For more details on estate planning, please visit: [www.dystoniacanada.org/legacy](http://www.dystoniacanada.org/legacy)

Yes, I want to join DMRF Canada's Legacy Society.

Please provide an email address: \_\_\_\_\_

Yes, I want to support DMRF Canada. Please add your selection below.

Yes, I want to make a one time gift to invest in critical dystonia research. Here is my gift of:

\$250    \$150    \$75    \$45    \$ \_\_\_\_\_

I am sending my cheque made payable to the Dystonia Medical Research Foundation Canada.

**Please note:** DMRF Canada has removed mailed in credit card information as a payment method to help safeguard donor information. You can still make a credit card donation or sign up to be a member of our Monthly Giving Team by visiting our website [www.dystoniacanada.org/donateonline](http://www.dystoniacanada.org/donateonline) or scan the QR Code. You can also call our office at 1.800.361.8061. **Charitable #12661 6598 RR0001**



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ADDRESS BOX



Cut along dotted line